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Active waiting list management: Potential usefulness in a community Eating Disorders
Service

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Abstract

We explored the usefulness of an initiative for managing a treatment waiting list in a community Eating Disorders Service. We sent 108 patients awaiting treatment an opt-in letter and, if necessary, a reminder three weeks later. Those who opted in were compared with those who did not. 67.6% opted-in and did not differ significantly from those who opted out on measures of eating disorder pathology and general functioning. However, they had waited less time. Opt-in letters may help to identify those who no longer want to access services, thereby allowing resources to be directed towards those who still want treatment.

Introduction

Management of waiting lists for mental health treatment in the UK and worldwide is becoming an increasing focus for health providers. The presence of long treatment waiting lists can demotivate patients and referrers, and cause significant costs (Jones & Bhadrinath, 1998; Tatham, Stringer, Perera, & Waller, 2012). Waiting times have also been found to be a robust predictor of failure to attend an initial appointment (Bell & Newns, 2004) and treatment dropout in a range of clinical settings. In a study exploring factors that impact engagement in substance misuse services, Claus and Kindleberger (2002) found that individuals with a shorter wait after assessment were more likely to attend an initial treatment appointment. Similarly, exploring predictors of dropout from out-patient enhanced cognitive behaviour therapy for eating disorders (CBT-E), Carter et al. (2012) reported that time spent on the waiting list (days between the date of referral and first active treatment session) was a significant predictor of dropout; most treatment completers waited less than five months, whereas those who dropped out waited an average of six months, with some patients waiting up to a year. Within eating disorders (EDs) it is widely recognised that treatment should be accessed at the earliest opportunity (NICE, 2004) and in community services a long delay in starting treatment can increase the risk of losing the therapeutic engagement established at assessment. Waiting times in community mental health clinics vary, with studies reporting waiting times of less than four weeks (Bell & Newns, 2004) to more than four months (Byrne, Fursland, Allen, & Watson, 2011; Foreman & Hanna, 2000) and up to 1-2 years (Lee, Ng, Kwok, & Fung, 2010).

However, whilst waiting times have been found to be a relatively robust predictor of treatment dropout, only a few studies have explored the potential impact of actively managing treatment waiting lists. Tatham et al. (2012) contacted 116 patients on a cognitive behaviour therapy (CBT) waiting list asking them to opt in or out of treatment. Following an

initial letter and a reminder sent three weeks later, 69% of patients chose to remain on the waiting list. This reflects previous findings (Carmen, Shah, Gilbert, & Russell, 2007) and also mirrors that found in a child and adolescent mental health service (Jones, Lucey, & Wadland, 2000).

Previous studies have also explored whether opt-in schemes discriminate against any particular patient sub-group, and findings suggest no differences between those who opt in or out of treatment waiting lists in relation to age, ethnicity, or body mass index (Bell & Newns, 2004; Tatham et al., 2012). Tatham et al. (2012) did not find any associations between ED diagnosis or general psychopathology and opt-in. They also examined the impact of a reminder letter by comparing three groups: opted in immediately; opted in after a reminder letter; and never opted in. They found that those who failed to opt in after the initial letter reported higher levels of psychoticism, depression, and borderline personality disorder cognitions at assessment although these group differences disappeared following the reminder letter. The authors concluded that patients who were asked if they wanted to remain on a waiting list were not disadvantaged by their psychological characteristics, as long as they are sent a reminder letter.

Whilst previous studies have compared those who opt in or out on a variety of baseline characteristics, such as age, weight and eating disorder cognitions, it remains unclear as to whether severity of behavioural symptoms or degree of functional impairment predicts opt in. The broader application of opt-in initiatives also remains poorly understood. We report on an opt-in procedure that was used as part of a clinical strategy to manage a psychological therapy waiting list in a community Eating Disorders Service (EDS). In contrast to Tatham et al. (2012) who focused on the management of a waiting list for CBT, this waiting list consisted of all patients waiting for a range of evidence-based psychological interventions for EDs, including guided self-help, CBT, cognitive analytic therapy, and focused

psychodynamic psychotherapy. In common with Tatham et al., we used measures that form part of routine assessment at the EDS. The current study thus aims to explore differences between those who opted in and those who did not, in relation to demographics, ED diagnosis, cognitive and behavioural ED presentation, general psychopathology and length of wait (time spent on the waiting list from assessment to being sent the opt-in letter). We also report the percentage of patients who actively engaged in treatment and the percentage who opted out but were subsequently re-referred in the six months following discharge.

Method

Clinical Setting

As part of routine clinical practice all patients referred to the service are seen for an assessment during which the 16th Edition of the EDE (Fairburn, Cooper, & O'Connor, 2008) is completed and information relating to demographics, current personal circumstances, personal history, and mental state is collected. Patients are also asked to complete measures of depression, psychological distress, and attachment style. This information is used to gain a greater understanding of comorbidity and underlying psychopathology at initial presentation (e.g., see Braun, Sunday, & Halmi, 1994; Ward, Ramsay, Turnbull, Benedettini, & Treasure, 2000). Decisions regarding treatment are made at a weekly team meeting and are informed by data gathered from the measures and the clinical interview. Allocation for treatment is primarily based on clinical risk; those presenting with high levels of risk related to medical presentation, including rapid deterioration, being prioritised for treatment. Individuals presenting with lower levels of clinical risk are placed on a standard treatment waiting list. Following assessment, patients are either contacted by telephone or seen for a further appointment (depending on patient preference), and potential treatment options are discussed and agreed with the patient. It is also explained to patients that there is a wait for treatment of

several months and in the meantime patients are encouraged to remain in regular contact with their general practitioner. Patients were not told about the opt-in letter at the time of assessment as this was the first time such a procedure had been implemented. Given that the standard waiting list had increased to just over one hundred patients, it was decided to implement an opt-in procedure based on that reported by Tatham et al. (2012). This involved sending an opt-in letter, followed by a reminder letter three weeks later. Three weeks after this, patients who did not respond or who opted out of therapy were formally discharged. A reminder letter was sent so as not to marginalise any sub-group of patients from accessing treatment (Tatham et al.).

Procedure

One hundred and eight patients who had been waiting for a minimum of two weeks were sent an opt-in letter, a reply slip and a self-addressed envelope. The letter stated that the service was aware that the individual had remained on our treatment waiting list since their initial appointment. It was stated that, in order to minimise the wait for treatment, individuals were being asked if they still wished to access treatment. The letter asked if the patient would either contact the service directly on the telephone number provided or complete and return the enclosed reply slip in the envelope provided. The patient was thanked for taking the time to read the letter and respond, and it was made clear that it was hoped that though writing we would be more able to direct our resources to those who still wanted to be seen for treatment. Patients were encouraged to contact the service if they had any questions. The reply slip included the patient's name and asked them to indicate, using a tick box, whether or not they wished to remain on the waiting list. Those who did not wish to remain on the waiting list were asked to indicate any of the following reasons: (1) I have sought or plan to seek treatment elsewhere; (2) My eating difficulties have improved and I feel I no longer need

treatment; (3) Other (with a space for free text). A reminder letter was sent to those who did not respond within three weeks, and they were given a further three weeks to respond. This letter summarised the date and context of the initial letter and once again asked for confirmation of whether or not the patient wished to remain on the treatment waiting list. A further reply slip and self-addressed envelope were enclosed. Those who opted to remain on the waiting list were sent a letter confirming this, with clarification that a therapist would be in touch as soon as a therapy slot became available. Those who did not respond within three weeks of being sent the reminder letter were discharged, and this was confirmed in a final discharge letter. Potential concerns about risk issues were discussed with patients' GPs prior to discharge and in the final discharge letter it was made clear that patients could contact the service if they did wish to remain on the waiting list. Alternatively, they could seek a re-referral at a later date if needed. Attendance at the first session of treatment was recorded for those who opted in.

Measures

Demographic. Socio-demographic data relating to age, gender and ethnicity were collected at the time of assessment.

Eating Disorder Pathology. Eating disorder pathology was assessed using the Eating Disorder Examination (EDE 16.0) (Fairburn et al., 2008), a semi-structured interview that generates subscales assessing dietary restraint, weight concern, shape concern, and eating concern, as well as frequency ratings for ED behaviours, such as objective bulimic episodes (OBEs), self-induced vomiting and laxative misuse. The EDE was used to generate ED diagnoses (DSM-IV).

Depression. The Beck Depression Inventory (BDI-II; Beck, Steer & Brown, 1996) was used to provide an index of depressive symptomatology. Psychometric properties of the BDI are well established (Beck et al., 1996) and internal consistency in the current sample was excellent ($\alpha = .93$, $n = 74$).

General Functioning. The Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM; Evans *et al.* 2000) is a brief self-report measure that assesses subjective well-being and functioning. It has been suggested that only 28 items (all items minus the six risk items) are sufficient for indicating reliable and useful change (Lyne, Barrett, Evans, & Barkham, 2006) and so this was used in the current paper. Cronbach's α for this subscale was .93 ($n = 85$).

Attachment style. The Attachment Style Questionnaire (ASQ; Feeney, Noller, & Hanrahan, 1994) was used to measure attachment style. This is a 40-item self-report questionnaire that provides five subscales: *confidence in relationships*; *need for approval*; *preoccupation with relationships*; *discomfort with closeness*; and *relationships as secondary*. Higher scores on the *confidence in relationships* subscale indicate more secure attachments, whilst higher scores on the other four subscales indicate insecure attachments. Cronbach's α for each subscale in the current sample varied from .56 (Preoccupation with relationships) to .87 (Confidence in relationships) ($ns = 91-98$).

Data analysis. Groups were compared using independent samples *t*-tests and one-way analysis of variance (ANOVA) for continuous measures, and the χ^2 test for categorical variables.

Results

One hundred and three women (95.4%) and five men (4.6%) were sent the opt-in letter and reply slip. The mean age of the total sample was 30.79 (s.d. = 10.3, range 18-60), with a mean body mass index (BMI) of 22.2 (range = 14.4-53.8, s.d. = 5.9). Eight individuals were diagnosed with anorexia nervosa (AN, 7.4%), 38 with bulimia nervosa (BN, 35.2%), and 62 with eating disorder not otherwise specified (EDNOS, 57.4%). Eighty (74.1%) reported that they were “White British,” six were from other ethnic groups while two declined to answer and a further twenty (18.5%) did not provide any information regarding ethnic origin. The mean time spent on the waiting list was 31.7 weeks (range = 2-69 weeks, s.d. = 19.3).

Of 108 patients sent an initial letter, 66 (61.1%) responded with a decision to opt in. A further seven (6.5 %) decided to opt in following the reminder letter. Sixteen (14.8%) indicated that they did not wish to remain on the waiting list. Eight of these (50%) reported improvements, two (13%) had sought treatment elsewhere and six (37.5%) did not specify a reason. Nineteen of the 108 (18%) did not respond to either of the opt-in letters.

There were no significant differences between the two groups (opt-in and opt-out) on demographic variables or psychiatric pathology (see Table 1). However, time spent on the waiting list was significantly different, with those who opted in spending less time on the waiting list than those who opted out ($t(106) = 3.560, p = .001$).

Insert Table 1

In view of the difference between those who opted in and those who opted out, the impact of the reminder letter was tentatively explored, creating three groups: opted in immediately; opted in after reminder; and never opted in. Those who opted in immediately and those who opted in following the reminder letter had waited a similar length of time,

considerably shorter than the mean wait of those who did not opt in (see Table 2). Due to small samples sizes, the impact of the reminder letter was not explored using statistical analyses.

Insert Table 2

Seventy-three participants opted to remain on the waiting list, of whom 54 (73.97%) attended their first treatment session, one (1.4%) attended following a second appointment letter, one (1.4%) had moved out of area, and thirteen (17.8%) did not attend. Four patients (6.8%) remained on the waiting list as they were currently receiving treatment from other mental health services.

Of those who were considered to have opted out of treatment during the initiative (19 who did not respond to the opt-in letter and 16 who opted out), none were re-referred in the 6 months following the initial opt-in letter being sent.

Discussion

Findings suggest that ED treatment waiting lists might be significantly reduced through use of an opt-in procedure (see also Hawker, 1994); in the present sample, 32.4% opted out of treatment. In line with previous findings, no association was found between opt-in rate and ethnicity, age, BMI, ED diagnosis, or severity of ED psychopathology (Tatham et al., 2012). Furthermore, no association was found between opt-in rate and severity of ED behaviours in the month before assessment (OBEs, SBEs, self-induced vomiting and laxative misuse), supporting the notion that opt-in letters do not marginalise any sub-group of patients from accessing treatment (Tatham et al., 2012).

The number of individuals with AN in the current sample was identical to that of Tatham et al. (2012) (although the sample size differed slightly) and rates of BN were lower. This latter finding may be a reflection of the different type of waiting list; individuals with BN are typically recommended CBT, whereas the current waiting list was for a range of evidence-based psychological therapies (including CBT, cognitive analytic therapy and focused psychodynamic psychotherapy). However, individuals with AN in the present study may be under-represented due to the frequent need to prioritise individuals for treatment on physical health grounds. Nonetheless, the general pattern of diagnoses in the current sample was similar to that previously reported in community studies (Turner & Bryant-Waugh, 2004). No association was found between opt-in rate and level of general psychopathology, including depression, attachment and subjective well-being, in contrast to that reported by Tatham et al.

The mean waiting time (from initial assessment appointment to being sent the opt-in letter) of 31 weeks reported in the present study is less than that commented upon by Lee et al. (2010) but longer than the waiting times reported in other studies (e.g., Tatham et al., 2012; Byrne et al., 2011), and it was because of this considerable wait that an opt-in initiative was implemented. A significant association was found between opt-in rate and time spent on the waiting list; further analysis suggested that those who waited longer were less likely to opt in. The mean waiting time was 27 weeks for those who opted in and 40 weeks for those who opted out. This reflects previous findings that those waiting for approximately 30 weeks or longer are more likely to opt out or not attend an initial assessment appointment (Foreman & Hanna, 2000; Tatham et al., 2012). This finding highlights the importance of keeping waiting lists to a minimum (NICE, 2004), but it is also important to note that 50% of those who requested to come off the waiting list indicated that their eating difficulties had improved. Foreman and Hanna (2000) suggest that significant numbers of those attending for

assessment at psychiatric clinics may have “transient problems” (p. 213), which may remit untreated. Our findings suggest that this may apply to a proportion of ED patients.

Of those who opted in, approximately 75% attended their initial treatment appointment, similar to that reported for a CBT waiting list (Tatham et al., 2012). Furthermore, in the six months following the initial letter no-one who had been discharged was re-referred. This further supports the use of an opt-in procedure as a method for identifying those who no longer require treatment as well as those who genuinely no longer wish to seek help. This in turn is likely to have a positive impact on appointment attendance rates, thereby allowing services to focus resources towards those who are actively wanting treatment.

The current study has a number of limitations. This initiative was only conducted at one clinic and the total sample size was small. The issue concerning sample size was of particular relevance for those with AN. It should also be noted that the measures of general psychopathology administered as part of the routine clinical assessment are periodically reviewed and revised by the service. As a consequence of this, some participants on the waiting list had completed different sets of assessment measures, and thus the measures reported in this paper were not completed by all participants. Results should therefore be treated with caution and further work might usefully look to replicate this initiative with larger sample sizes. It is also important to note that what is meant by ‘waiting time’ varies across studies; time between referral and initial assessment, time between referral and start of treatment, and time between assessment and start of treatment have all been reported, and we must be aware of these varying definitions when interpreting the existing literature.

The current findings support the use of an opt-in letter as part of a strategy to manage EDS treatment waiting lists. Opt-in rates were not associated with socio-demographic variables, ED diagnosis, severity of ED presentation or aspects of general psychopathology. Length of treatment wait was associated with opt-in, with those who had waited longer being

less likely to opt in. Whilst a wait for treatment might allow some an opportunity to recover without the need for specialist input, it is important that the impact of longer waiting times is minimised as far as possible. The use of an opt-in letter may help services to retain a connection with those who still wish to access treatment, whilst also providing a time efficient means of identifying those who no longer need or wish to access input. Future research might usefully explore the impact of differing waiting times, as well as the potential usefulness of employing an opt-in letter as part of a routine service strategy. Such research would help to further clarify the potential role that an active waiting list initiative might usefully play in ensuring that resources are targeted towards those who continue to need and actively want treatment.

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